

## GUEST EDITORIAL

# The National Cancer Data Base: What Does It Mean to the Community Surgeon?

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Surgeons have justly taken pride in their role in cancer care, but many are unaware of the National Cancer Data Base (NCDB) and the ways in which it works with community hospitals and community surgeons to improve cancer patient care. The NCDB traces its origin to a remarkable collaboration between the American Cancer Society and the Commission on Cancer of the American College of Surgeons, dating back to 1913 [1,2]. Data collection began in 1920, with the establishment of the bone sarcoma registry. Patient care evaluation (PCE) studies began in 1976, and in 1988 the American Cancer Society provided the initial 2-year planning grant for the formal establishment of what is now known as the NCDB. Now celebrating its first decade, the NCDB continues to be jointly governed by both the Commission on Cancer of the American College of Surgeons and the American Cancer Society [3–5].

At its foundation, the NCDB had three objectives: (1) to establish a national data base to collect information on patient care and outcomes and subsequently disseminate analyses of this information to the medical community; (2) to improve cancer programs in hospitals approved by the American College of Surgeons' Commission on Cancer and other cooperating hospitals by providing annual reports of national, regional, and hospital data; and (3) to speed the transfer of information on cancer research advances into cancer patient care [6]. This has recently been concisely restated: the purpose of the NCDB is to encourage, support, and facilitate data-driven cancer control at the local, regional, and national levels.

The NCDB is one of three national cancer registries that serve the United States. The other two are the Sur-

veillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute and the National Program for Cancer Registries (NPCR) of the Centers for Disease Control. The operating procedures of the three registries differ somewhat, reflecting the goals of their different sponsors and constituents.

SEER began as a data base to collect information from 10 cities and, thus, is population-based. It now runs 11 registries, some of which cover entire states, and is estimated to contain data on about 13% of cancer patients in the United States. Regional representation is problematic; for example, SEER retrieves limited information from southern states. For those regions that are included in the data set, SEER provides a complete population-based data set that may be followed over time, thus facilitating analyses of incidence trends [2].

Like SEER, the NPCR is population-based. It collects its data through state registries and does not have a data base at this time. Although these state registries now contain information on more than 90% of cancer cases diagnosed in the United States, the NPCR does not yet collect data on treatment and, in some cases, does not collect data on follow-up and survival. Both SEER and the NCDB do collect data on follow-up and survival. Perhaps reflecting the organizations which sponsor it, the NCDB contains particularly rich data on treatment, in-

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cluding detailed information on surgical patterns of care. All three registries contain information on patient characteristics, incidence and types of cancer, and mortality rates [2,4].

### SOURCES OF DATA

The NCDB collects its data from hospital registries and, thus, is said to be "community-based." Hospitals represent smaller regions from which to collect data than cities or states, in that for most hospitals the catchment area is the immediately surrounding community [4,5]. The shift in site of cancer care from hospitals to outpatient settings that may or may not be hospital-affiliated has challenged all registries. To give an obvious example, most patients with skin cancer are treated in the outpatient setting, as are increasing numbers of women with breast cancer. In many instances, pathologists and other physicians working outside of the hospital cooperate by sending data to a registry or directly to the NCDB.

The headquarters of the NCDB is at the American College of Surgeons in Chicago. Here, the data submitted to the NCDB is subjected to edit checks and analyzed [7]. Each year, individual reports are sent back to every contributing hospital. These reports allow individual contributing hospitals and clinicians to make stage-specific comparisons of their own treatment methods and survival for each of the 38 sites currently represented in the NCDB. Individual hospital data is displayed side by side with national data, facilitating comparison. Data dissemination and interpretation is aided by the Cancer Liaison physician volunteer network, 60% of whom are surgeons. Two volumes of "success stories" effectively demonstrate how this system is being used to improve cancer care at the local level [8,9]. The cost of central NCDB operations for the most recent years is approximately \$1.64 per annual incident case [4].

In the NCDB's first year, 501 hospitals provided data on 232,577 cases (24% of the cancer cases diagnosed in the United States in 1985). The NCDB estimates that it collected information on 57% of all cancer cases in 1994 and 52% in 1995 and projects in excess of 70% in 1996 and 80% by the year 2000. The NCDB now has data on large numbers of the most common cancers, for example, over 700,000 cases of breast cancer and over 558,000 cases of prostate cancer, thus allowing reliable subset analyses to be made. For rare malignancies, the NCDB has accumulated sufficient numbers of cases to provide reliable statistical information about those cancers, for instance, most recently 2,918 cases of cancer of the eye and 12,564 cases of nasopharyngeal cancer.

These cases are reported from differing types and sizes of hospital, different medical practices, and patients of varying ethnic origins and income levels (the latter extrapolated from zip code of residence). Some states are not well represented in the NCDB database, perhaps as a

consequence of relatively sparse resident population and low levels of hospital participation. To compensate in part for this difficulty, states are aggregated into 6 regions for purposes of geographic analyses (Northeast, Southeast, Midwest, South, Mountain, Pacific). Regional differences in care and time trends in patterns of care (for example, in the use of breast-conserving surgery for cancer of the breast) can then be analyzed and reported [10,11]. Although the NCDB is not population-based, it has been reassuring to note that the distribution of cancers, segmented by 43 primary sites and by 9 age categories, is remarkably similar in the 6 geographic regions [5,12]. This suggests that our samples are equally representative of the geographic regions with regard to site and sex (given the assumption of uniform incidence). It is, of course, possible that these cancers are not evenly distributed among the 6 regions but appear so because of a bias in our findings which offsets these differences or that there is an equal and consistent bias in all regions causing omission of some variants of cancer cases. These latter possibilities appear much less likely [5].

Oversight for the NCDB is vested in two committees and 16 site-disease teams of clinicians. The NCDB assesses patient care by using both traditional hospital cancer registry data collected annually (longitudinally) and periodic focused PCE studies (cross-sectional data). Under the Commission on Cancer, the NCDB works closely with the national network of hospital Cancer Liaison Physicians (representing over 2,000 US hospitals) and the Hospital Approvals Program (which now includes nearly 1,600 hospitals).

### PROBLEMS AND SOLUTIONS

No large national data base is without problems. Data received by the NCDB often lacks information on one or more variables. Accurate American Joint Cancer Committee tumor staging is crucial. Close collaboration between the hospital registry staff, who are acutely aware of the need for accurate documentation, and clinicians is important. Software idiosyncrasies cause difficulties. Funding for tumor registries is especially problematic in an era of dwindling financial resources. NCDB data may underrepresent some populations. Some states contribute few cases, as previously mentioned. Cancers from some regions or from some ethnic groups may be underreported for a variety of reasons. A comparison of NCDB and SEER data showed that the NCDB data contained less complete information about Hispanic ethnicity of patients, for example [2-6]. The NCDB is constantly striving to improve the accuracy of the data.

Cancer patients who receive diagnosis and treatment at a US hospital represent the bulk of cases reported to the NCDB. By extension, cases of undiagnosed cancer (such as patients who die without having their cancer diagnosed or cases discovered at autopsy) are not included.

Collection of data on the increasing numbers of cancer patients treated outside of hospitals is difficult.

### FUTURE OF THE NCDB

While noting these problems, we believe that the potential value of this comprehensive data base is enormous. More than 190 papers have been written using NCDB statistics, and an additional 147 papers have come from PCEs. An annotated bibliography of NCDB publications by tumor site, further information about the NCDB, and tabular data for many tumors are available at the NCDB website ([http://www.facs.org/about\\_college/acsdept/cancer\\_dept/programs/ncdb/ncdb.html](http://www.facs.org/about_college/acsdept/cancer_dept/programs/ncdb/ncdb.html)). Recognizing the value of this data base and its important role in improving cancer care, the Commission on Cancer mandated in 1996 that any hospital desiring to receive or keep approval of its cancer programs by the commission must report all cancer cases to the NCDB [4,5]. As the number of participating hospitals has increased, the representativeness and completeness of the data set have improved. With the accumulation of years of more accurate and complete data, the statistics derived from these data will be more and more authoritative, with fewer possibilities of statistically derived errors.

Two new initiatives by the sponsoring organizations, the American College of Surgeons Oncology Trial Group and the Infonet System of the American Cancer Society, build on the strength of the NCDB and will enhance it immeasurably. Distribution of information is increasingly electronic, and the speed of dissemination is thus potentially limited only by the time required to accrue and analyze the data.

The majority of data contributed to the NCDB comes from community hospitals. In 1995, for example, teaching, government, and National Cancer Institute-designated cancer centers contributed just 21.8% of cases, the remainder coming from community hospitals with approved programs and hospitals lacking approved cancer programs. The NCDB is thus a resource in which the community of surgeons, working in hospitals of all sizes

throughout the United States, can take pride and from which "data-driven improvements in cancer care" can be derived [14]. The NCDB relies on and thanks these physicians and hospitals for their energy, enthusiasm, and commitment to excellence. As it meets the challenges of the new millennium, the NCDB will use these data to inform us on ways to reduce site-specific morbidity and mortality.

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